

Urging The Passage Of HR 1849 To Create A Federally Led And Financed Initiative For Early Diagnoses And Appropriate Treatment Of Hereditary Hemorrhagic Telangiectasia

Referred to: The Public Health and Social Services Committee (Chairman Lopez and Legislators Allen, Belfiglio, Litts and Provenzano)

Legislator Kevin A. Roberts offers the following:

WHEREAS, Hereditary Hemorrhagic Telangiectasia (HHT), also known as Osler-Weber-Rendu Syndrome, is a multi-organ manifestation characterized by tangled blood vessels in the brain, lungs, liver, nose, skin, and intestines; and

WHEREAS, HHT is a common “rare” disorder affecting an estimated 1 in 5,000 people; and

WHEREAS, 90% of individuals with HHT experience moderate to severe nosebleeds which are not yet diagnosed due to widespread lack of knowledge by medical professionals; and

WHEREAS, HHT can result in stroke, hemorrhage, or heart failure; and

WHEREAS, HHT tragedies can be prevented through early diagnosis and treatment; and

WHEREAS, by Resolution No. 251 dated and duly adopted on the date hereof, the Ulster County Legislature proclaimed June 2015 As Hereditary Hemorrhagic Telangiectasia (HHT) Awareness Month in Ulster County; and

WHEREAS, the HHT Diagnosis and Treatment Act HR 1849 was introduced in the House of Representatives on April 16, 2015 as part of the 114th Congress; and

WHEREAS, HR 1849 would be the first to create a federally led and financed initiative for early diagnoses and appropriate treatment of hereditary hemorrhagic telangiectasia by requiring the Centers for Disease Control and Prevention to conduct surveillance initiatives, start an internal HHT resource center and conduct public awareness programs, and authorize the appropriation of \$5 million per year for the next five years to be used to improve early detection, screening, diagnosis and treatment of HHT; now, therefore, be it

Resolution No. 252 June 16, 2015

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Treatment Of Hereditary Hemorrhagic Telangiectasia**

RESOLVED, that the Ulster County Legislature calls on United States President Barack Obama, United States Senators Charles Schumer and Kirsten Gillibrand, United States Representative Chris Gibson, to unite in creation of a federally led and financed initiative for early diagnoses and appropriate treatment of hereditary hemorrhagic telangiectasia through the passage of HR 1849 in the 114th Congressional Session; and, be it further

RESOLVED, that the Clerk of the Ulster County Legislature shall forward copies of this resolution to the President of the United States, to the President of the Senate and the Speaker of the House of Representatives of the United States Congress, United States Congressman Chris Gibson, United States Senator Kirsten Gillibrand and United States Senator Charles Schumer, and Centers for Disease Control Director, Dr. Tom Frieden; and, be it further

RESOLVED, that the Clerk of the Ulster County Legislature shall forward copies of this resolution to New York State Governor Andrew Cuomo, New York State Senators John Bonacic, William Larkin, James Seward, and Cecilia Tkaczyk, and Assemblymen Kevin Cahill, Peter Lope, Frank Skartados and Claudia Tenney, New York State Department of Health Commissioner, Dr. Howard Zucker,

and moves its adoption.

ADOPTED BY THE FOLLOWING VOTE:

AYES:

NOES:

Passed Committee: Public Health and Social Services Committee on _____.

FINANCIAL IMPACT:
NONE